

CANADIAN AUTISM LEADERSHIP SUMMIT 2020: Evaluation Report

2020/ 10



CASDA  ACTSA

Dear Summit attendee,

Thank you for joining us at the 6th Annual Canadian Autism Leadership Summit last week.

For many, this was a first full virtual conference experience. Despite this, over the course of the conference, dynamic conversations still took place. There were countless stories of meeting new people, engaging with different perspectives and learning new ideas. This illustrates the strength of our community.

This year's Summit theme was "Connect. Inform. Act. Sustain." We focused on how we could collectively deepen the conversations linking policy, practice, and data – and support the federal government to move forward on their commitment to develop and implement a National Autism Strategy.

Thank you to those of you who participated in our post-summit surveys and polls. We truly appreciate your feedback to help make the Summit even better next year, whether it be in-person or virtual.

In this report, you will learn about who attended, what people thought of the content and experience of this year's Summit, opinions on the polling questions from each session, and highlights from social media. We summarized the responses in the report but also appended the full results at the back of the report.

At CASDA, we love to hear from you, the community, as we move your ideas, concerns, and suggestions forward to support the government's development of a National Autism Strategy.

If you want to view talks that you missed, **here is where you can access them** for one more week. After that, members will have exclusive access to presentations that we have consent to host and share on our website.

Best wishes, The CASDA Team

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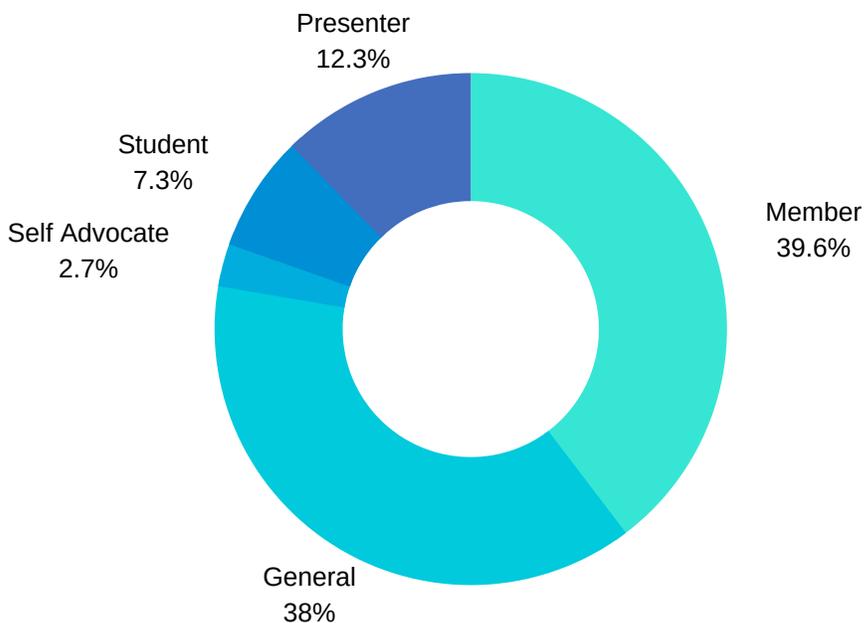
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01 Attendance

TOTAL Registrants: 260



CASDA Members: 103

Self-Advocate: 7

Presenter: 32

Student: 19

General Admission: 99

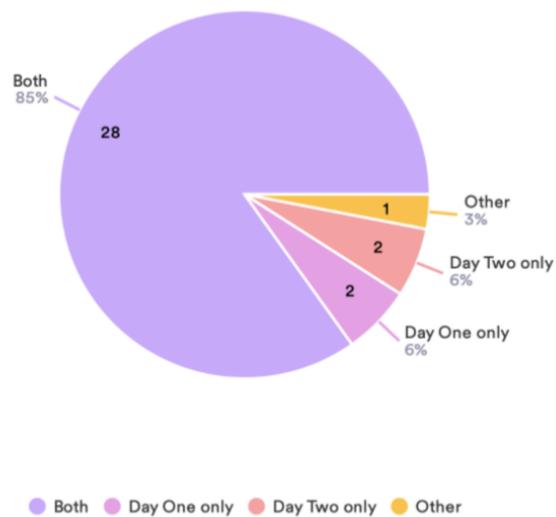
Attendee location:

52% Ontario, 18% Alberta, 14% British Columbia, 10% Quebec, the rest were from other provinces and territories, including a few international attendees.

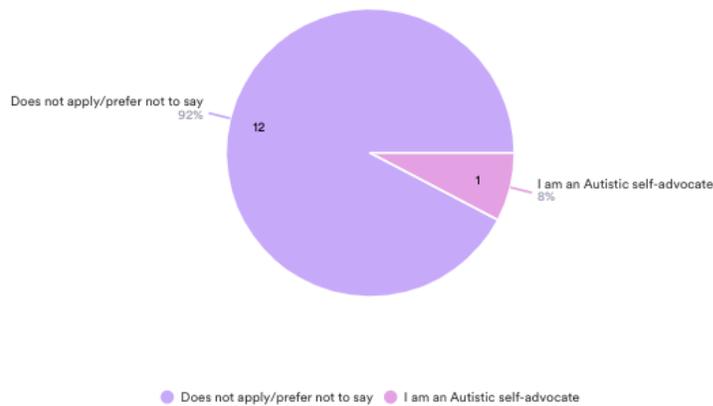
Note: Only 241 of the 260 registrants indicated their province location in Eventbrite.

Event Feedback 02

- **What days did you attend?**

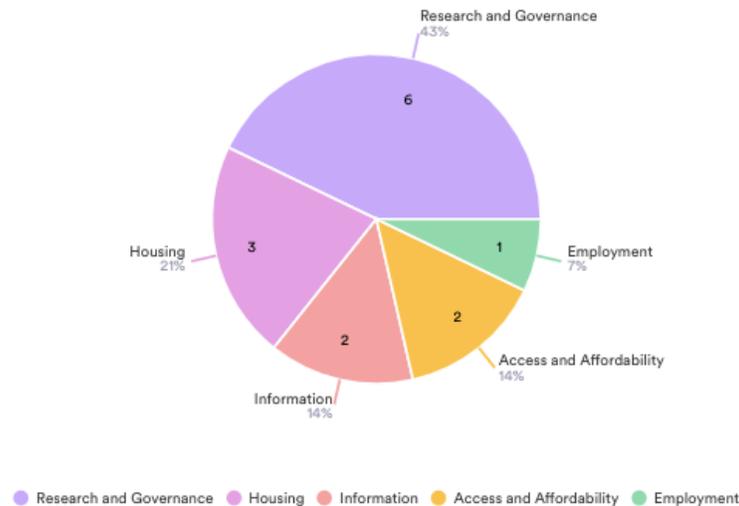


- **Are you an Autistic self-advocate?**



Event Feedback 02

- **Please tell us about the organization you work for.**



- **Please tell us what you thought about the Summit**

- 94% of respondents thought that the information presented would be useful to their work
- 88% of respondents thought that attending the Summit has increased their knowledge of the work related to a National Autism Strategy
- 76% of respondents' expectations were met
- 89% of respondents thought the Summit meets its aims and objectives
- 100% of respondents indicated that they will attend future Summits
- 78% of respondents would invite another person to attend the Summit next year

Event Feedback 02

How likely are you to recommend the next Summit to a friend/colleague?



- Our Net Promoter Score (NPS) was +18.
- Detractors = 21%
- Passives = 39%
- Promoters = 39%
- The NPS is the leading metric for calculating client satisfaction.

WHAT YOU SAID IN THE POLLS ...

"Prioritize autistic voices. Listen to us, implement what we are asking for, and compensate us."

"THERE SHOULD BE A FEDERALLY MANAGED FUND SIMILAR TO REGIONAL DEVELOPMENT FUNDS."

"Reconciling between all the different policies across the provinces and territories."

"Getting provinces and territories to have a system to talk, share, collaborate and plan standards that are centered on the Autistic individual..."

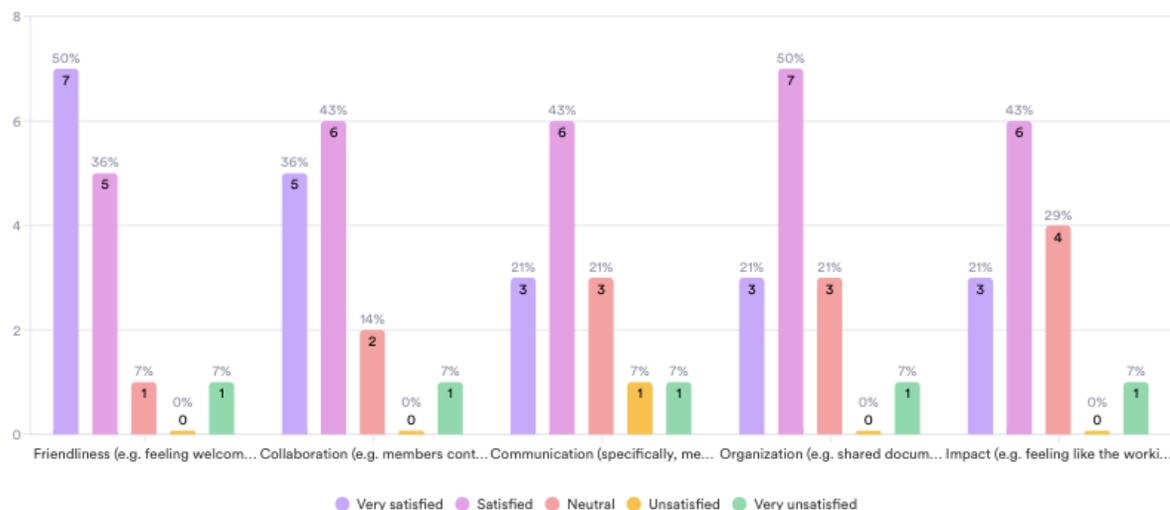
"Intersectionality - creating safe, productive spaces for other minority groups (race, gender, sexuality, disability, etc.)"

"Sustained supports throughout the employment lifecycle. For example, coaching, mentorship and related supports..."

"FOR AUTISTIC CANADIANS TO LEAD AN INFORMATION COLLECTION AND DISSEMINATION STRATEGY..."

"Making connections to indigenous communities. Increasing diversity, equity, and inclusion to hear and have conversations for cultural awareness and opening up discussions on how we can do better."

Event Feedback 02



Why did you attend the Summit?

- The majority of respondents attended the Summit for educational and networking opportunities.

Did you get what you intended to?

- Overall, the majority of respondents stated that they got what they intended to at the Summit. Of those that indicated that they were not satisfied with the Summit, technological difficulties were one of the main reasons stated. Additionally, content was cited frequently as a reason for both satisfaction and dissatisfaction with the Summit. Respondents were split on whether the content was great, too much, too little, outdated, informative, and too focused on autism facts/interventions to name a few. Finally, the ability to network was another common reason for attendee's level of satisfaction.

Event Feedback 02

Did you feel that you were meaningfully included?

- Respondents overwhelmingly stated that they felt that they were meaningfully included. Respondents indicated that the atmosphere of the Summit was welcoming, educational and open. There were some respondents that expressed concerns regarding the polling, either not knowing about them, the complexity of the language or confusion surrounding the process.

What parts of the Summit informed you about a NAS?

- In the survey, a large majority of individuals indicated that the Summit overall informed them about a NAS. Many enjoyed the design of information surrounding a NAS being weaved throughout the Summit. Particular sessions that were consistently highlighted as informative of a NAS were the Keynote presentations, the speakers, and the KBHN-CASDA Policy Working Groups policy briefs' session. Additional common responses, although less so, were the Kahoot game and the Chat function.

What helped you in your advocacy related to a NAS?

- The majority of respondents indicated that there were quite a lot of aspects at the Summit that aided their advocacy in relation to a NAS. They underlined that the presentations, the Equity Panel and networking opportunities were significantly helpful. While there were a handful of respondents that indicated that there was little to no help in relation to their advocacy due to the limited advancements in the creation and implementation of a NAS.

Event Feedback 02

How many new connections did you make?

- On average, respondents indicated that they made 3 new connections. Some made even more, at about 5 connections, some individuals indicated even more. While other respondents noted that they made less. This was for the most part explained as being due to not fully participating and connecting with old connections.

What was the most valuable/beneficial aspect of the Summit?

- Predominantly respondents wrote that the networking opportunities at the virtual tables were the most valuable/beneficial aspect of the Summit. Others noted that the presentations, posters, the Equity Panel, and the speakers were the most valuable/beneficial aspect of the Summit.

What was the least valuable/beneficial aspect of the Summit?

- Overall, respondents noted for the most part that technology was a great barrier, with connectivity difficulties, tech talk dominating the chat feature, and difficulties regarding the poster presentation format. Others noted that the posters were the least beneficial along with the Kahoot game. While other respondents stated that there wasn't any aspect that was the least valuable/beneficial.

General NAS Poll 03

What is the most important challenge facing the development of a National Autism Strategy?

- Stakeholders noted that cohesion and collaboration were the predominant challenges facing the development of a National Autism Strategy. In particular, autistic voices must be included in all aspects of a National Autism Strategy in a meaningful and equitable manner. Furthermore, getting governments across the country to collaborate in the creation, knowledge sharing, implementation of a NAS was also commonly selected as the most important challenge. Others noted that action during the pandemic and collaborating with PHAC also proved challenging.

What is the biggest opportunity or new/emerging area, method, or issue that needs CASDA investment and attention?

- Respondents primarily responded to this question by answering that engaging autistic Canadians was the biggest opportunity or new/emerging area, method, or issue that needs CASDA's investment and attention. Other common responses were in line with addressing controversies within the autism community directly, connecting with the government and focusing on the impacts of intersectionality. While other respondents wanted more attention and investment in participatory autism research and research into the under-researched areas surrounding the needs of autistic Canadians.

What are the basic standards of therapy, services and supports that autistic Canadians and their families should expect to receive, regardless of where they live?

- Responses to this question were extremely diverse, although a number of respondents highlighted the need for a variety of evidence-based therapies, services, and supports that were person-centred and needs-based. Others highlighted the need for said therapies, services and supports must be accessible to all Canadians no matter where they live. Some highlighted the need for Dx, prompt assessments and early intervention, other respondents stated the abolishment of ABA/IBI early intervention.

IGNITE Talk Reflections 04

How can we coordinate efforts across different contexts and provinces to capitalize on each other's strengths?

- Overwhelmingly, responses to this question were the need to prioritize autistic Canadian leadership, while also ensuring to prioritize engagement with many autistic Canadians. Other responses pointed to the need to engage with all stakeholders, including spaces to collaborate with broader communities, and focusing on collaboration and knowledge sharing at all levels, specifically at the grassroots level.

IGNITE Talk **04** Networks

How can we foster (and fund) inter-provincial collaborations among researchers and policymakers to share knowledge and generate much-needed comparative information about different approaches to Autism Spectrum Disorder services and their effectiveness?

- In responding to the question, many respondents pointed to the possibility of a national information exchange network, wherein all information related to Autism could be stored and accessed. Others highlighted the need to ensure that autistic Canadians were playing a central role in this process along with the need to engage with all stakeholders. Some respondents answered this question by suggesting federally funded collaboration, or collaboration funded by a NAS.

IGNITE Talk **04**

Employment

What immediate opportunities exist to expand the scope of employment data & information collected across Canada?

- A number of respondents noted the benefits of the Worktopia Project, while others pointed to a new program led by Autism Ontario as well as organizations such as Auticon Canada. It was also stated that autistic Canadians ought to be at the helm in collecting and disseminating information from said employment programs for autistic Canadians. What would you say are some gaps in federal and provincial employment programs for autistic Canadians? The responses to this question were extremely diverse. While some respondents pointed at the lacking supports for rural areas and a place that listed comprehensive supports, others pointed to the lack of follow-ups, sustained supports, and the lack of specific types of supports.

Panel: Addressing Disparities

04

Autistic organizations are underrepresented in CASDA's list of partners. What are some ways CASDA and autistic organizations can work together to ensure that autistic people are involved in conversations on a National Autism Strategy?

- In responding to this question, there was a range of suggestions from respondents. Some suggested stronger connections to indigenous communities and connections to diverse communities, others pointed to the need for placing autistic voices at the center.

What are some promising practices with engaging diverse communities (e.g. Indigenous)? How can we do better?

- Respondents highlighted that, currently, the Nishnawabe Aski Nation (NAN) has been working on a Special Needs Strategy, while others noted that we must put indigenous autistics in positions of power. Another suggestion was to create a network of smaller groups along with guides on how to engage with these smaller groups.

"THANKS VERY MUCH FOR THE OPPORTUNITY TO TAKE PART IN THIS CONFERENCE. IT WAS GREAT TO MEET SO MANY PEOPLE AND LEARN FROM THEIR EXPERIENCES. I LOOK FORWARD TO TAKING PART IN THE SUMMIT NEXT YEAR, HOPEFULLY IN PERSON THIS TIME."

THE CASDA LEADERSHIP SUMMIT IS ALWAYS A HIGHLIGHT OF MY YEAR!

"#CAL5 2020 I'M LOVING WHAT I'M HEARING AT THE @ASDALLIANCE CASDA SUMMIT TODAY..."

"SEE YOU NEXT YEAR FOR SURE!"



"THIS EXPERIENCE WITH @ASDALLIANCE WAS AMAZING, FULFILLING"

Here's What People Had to Say About The Summit

"CENTERING THE RESEARCH & THE SUPPORTS ON AUTISTIC INDIVIDUALS & ENGAGING WITH AUTISTICS AS WELL AS ALL OTHER STAKEHOLDERS IS BREATHTAKING, REFRESHING & ESSENTIAL."

"I was SO impressed by the amazing work that went into getting the summit ready ... Great topics and wonderful energy ..."

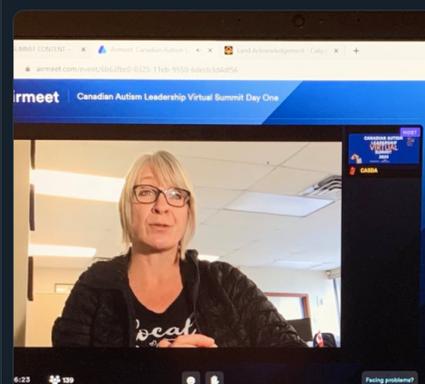
#CALSS2020



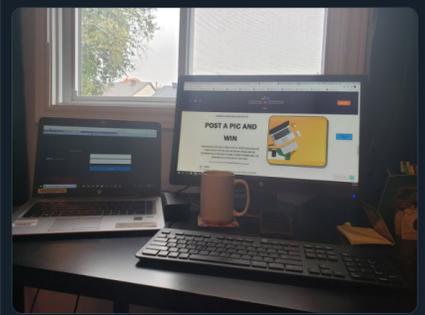
Karen Bopp @KarenBopp2
The Virtual Canadian Autism Leadership Summit is HAPPENING NOW. A great new way to connect across the country. #cals2020

4:24 PM · Oct 5, 2020 · Twitter for iPhone

Amy Lonsberry @amylonsberry
Thanks @PattyHajdu @SenatorMunson for kicking off #CALSS2020



Taylor LJ @TaylorLinsman
@ASDalliance I am ready for you! #CALSS2020 #virtual #innovation
Ps. Pick me!



6:18 PM · Oct 5, 2020 · Twitter Web App

Ally Garber @AllyGarbs
"The Prime Minister has entrusted me to work with provinces, territories, families, stakeholders and those with lived experience towards the creation of a National Autism Strategy." - @PattyHajdu casda.ca/statement-on-t... #CALSS2020 @ASDalliance

Statement on National Autism Strategy
CASDA WELCOMES GOVERNMENT OF CANADA'S CONFIRMATION OF A NATIONAL AUTISM STRATEGY This ...
casda.ca



Terry Batley @Grim_DarkStone
#CALSS2020 Relaxing and listening to CASDA presentations



10:32 AM · Oct 5, 2020 · Twitter for iPhone

The Sinneave Family Foundation @sinneave
We are pleased to participate in these important discussions! #CALSS2020

POSITION STATEMENT
It is a human right for all people to benefit from favourable conditions of work and to protect their right to work.
- Universal Declaration of Human Rights, United Nations
everyone has the right to work, to free choice of employment

Helen Ries @helenries
Appreciated @MattJDever presentation which included #evaluation of programs that serve #Autistic adults. How will the evaluation community respond around communication, #accessibility and capturing the diversity of stories. #CALSS2020

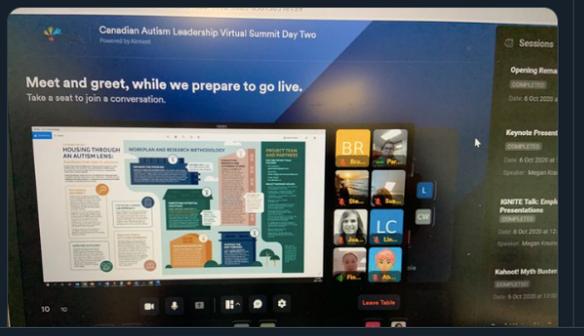


12:59 PM · Oct 5, 2020 from Montréal, Québec · Twitter for iPhone

Autism Yukon @yukon_autism
See this Instagram photo by @margaret_leslie_ instagram.com/p/CF-Arm9nbZ2/... Attending the CASDA Leadership Summit virtually this year. #CALSS2020 Thanks for putting on this event @ASDalliance The presenters have been great so far, and there are lots of chances to ask & interact.

2:49 PM · Oct 5, 2020 · Twitter Web App

Pari Johnston @JohnstonPari
So terrific 2 have so much interest at #CALSS2020 in our new "Housing Through an Autism Lens" social change lab in Ottawa. Really looking forward 2 working with all the potential new partners from across 🇨🇦 we met today! @helenries @TheRoyalMHC @MSAutismOntario @sinneave



Mackenzie Salt @Mac_at_Mac
Looking forward to attending the CASDA leadership summit in April and engaging in discussion about the blueprint for a #NationalAutismStrategy with so many people from different facets of the community. #CALSS2020

Jen Zwicker @jdzwicker
Amazing work by @ASDalliance @KidsBrainHealth policy fellows co-leading working groups and presenting their findings to inform a national autism strategy. Important recommendations and great to have a chance to discuss these at the #CALSS2020

CASDA @ASDalliance · Oct 5
HAPPENING NOW: Listen to @bfinlay05 @carolynabel @dggillbadesha @vanessatomas @SteveGentles share some of the work that is part of CASDA's strategy to help support the Canadian government to implement a national autism strategy.

Kids Brain Health @KidsBrainHealth
At 3 PM EST, catch the KBHN-CASDA fellows at #CALSS2020 for their session on Policy Brief Consultations.

There's still time to register:

CANADIAN AUTISM LEADERSHIP VIRTUAL SUMMIT 2020
PRESENTED BY CASDA ACTSA

Canadian Autism Leadership Summit 2020
eventbrite.com

Best Performing Content

05

CASDA @ASDalliance

"Summit 2020 is about one thing. Our ability to come together. As a community ...unite around what brings all of us together – the undeniable need for realizing the rights of Autistic Canadians, and the steps required to achieve it." @drjonlai #CAL2020



Reach a bigger audience

Get more engagements by promoting this Tweet!

Get started

Impressions	2,163
Total engagements	113
Detail expands	63
Likes	20
Profile clicks	15
Retweets	9
Hashtag clicks	5
Replies	1

CASDA @ASDalliance

"When we come together, better happens. This isn't about one of us, and it isn't about some of us, it's about all of us. Collaboration isn't a choice, it's the way forward. These 2 days was a beautiful example of that. Thank you all again for making it possible."- @drjonlai



Reach a bigger audience

Get more engagements by promoting this Tweet!

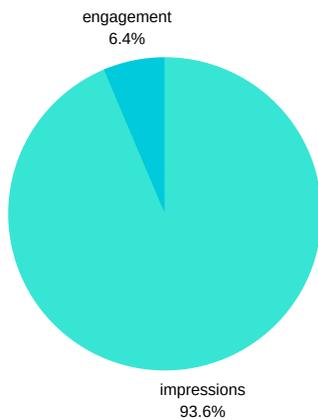
Get started

Impressions	3,701
Total engagements	143
Detail expands	74
Likes	27
Profile clicks	24
Retweets	14
Replies	4

05

By The Numbers

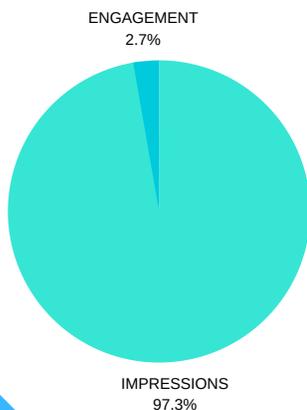
OCTOBER 5TH



IMPRESSIONS: 5325

ENGAGEMENTS: 362

OCTOBER 6TH



IMPRESSIONS: 10,177

ENGAGEMENTS: 287

05

By The Numbers

CASDA's Twitter Landscape During the Week of the Summit Period: October 5-9, 2020



CALS2020
Hashtag Use:

79

Impressions:

27.3k

↑32%

Mentions:

248

↑43%

Profile Visits:

538

↑53%

THANK YOU

CANADIAN AUTISM LEADERSHIP VIRTUAL SUMMIT 2020



PRESENTED BY  CASDA ACTSA



CASDA  ACTSA

Appendix 06

Event Feedback

We asked attendees the following questions, here's what they had to say.

WHY DID YOU ATTEND THE SUMMIT?

- I attended for the networking opportunities and learning about the field
- Networking and Understanding
- It is highly relevant to my job (I am the head of a department that provides care to people on the autism spectrum).
- The Summit has never failed to be incredibly informative and an incredible time to network. I've been attending it now for almost 5 years. While technical issues impacted this especially on Day * One, it ultimately did not diminish the flood of information that was put forward in this year's * Summit and networking was still possible. I attended to present a poster as well as to do networking and for professional development. There was also a great lineup of speakers.
- I attended the Summit to expand my knowledge base.
- Networking, speakers
- Speakers, education,
- Personal growth
- I find it interesting to know what is happening around the country so we can get better information and not to have to reinvent the wheel. Networking, Speakers, to speak
- I was part of the panelists for AWNNE as a Autistic Advocate.
- Networking, interest. I worked in the field for 40.5 years
- To hear the speakers and be able to compare the programs offered in my home province (BC) to those offered nationwide.
- I have attended all the Summits and wouldn't miss it.
- Speakers, knowledge exchange, networking
- Speakers/to hear about the National Autism Strategy/did not think networking would be possible due to format, but the 'table' arrangements facilitated more networking than I thought would be possible. Once one got accustomed to 'airmeet' and how it worked, it worked very well. Two days on ZOOM is very long, but actually it was less exhausting than I thought it would be.
- Information share and education.
- Connecting with others, learning what is going on in Canada

Appendix 06

Event Feedback

Did you get what you intended to?

- I much prefer being live in person but considering this is a new platform I think it was excellent and I believe I definitely got in some networking and learned so much about initiatives that are happening across Canada. It also provided me with an update on our national strategy.
- Somewhat. I was only able to get a seat at 2 tables each day and only 2 of the 4 topics were of high interest to me. One of the tables the speaker didn't even present and just commented in the chat box that we could ask questions if we had any. It was also extremely difficult to see a lot of the text on the posters.
- I also feel that my own son is underrepresented when it comes to Summits such as these. He is cognitively delayed, limited verbal and can not advocate for himself. I did appreciate seeing Jadan and Mike Lake present.
- I think the conference was done well, but towards the end of both days I felt like there was too much information to thoroughly process and register.
- Understanding the Action Needed and PLAN for the NAS.
- I did not walk away with major takeaways, but I did find some tidbits to think about. Why/Why Not: the session content was interesting, but we don't have a lot of cutting edge research, none of the political implications (that are so very pressing in Ontario) were addressed, and overall it wasn't evident that the content submission process was all that competitive.
- Yes, I did get what I intended to because of everyone's collective effort and will to make the Summit possible in the midst of everything COVID-19 related.
- I was not able to see some of the later talks on the first day because things went late and I had to pick up my child from daycare. That said, everything else I saw was quite good and I did get what I had intended to.
- Yes, and no.....I would have liked less riddles, and game playing and less networking in favour of more presentations and speakers.
- Very pleased with the virtual Summit. Good online networking opportunities. Great content.
- Yes. Good knowledge and ability to network with other organizations
- Yes.
- I was thinking this was more about "Autism facts" and interventions. So no
- Yes - I liked the concept of the posters at the table. It leads to better discussions as live often it is you and the presenter. This way we learned by listening to others questions, concerns and comments

Appendix 06

Event Feedback

- No, I was looking for more Networking and time at Tables to know what people are experiencing
- Yes because it was important to address the challenges faced for Autistic Women and Non-Binary individuals face in the employment world.
- Fell short technologically, particularly Day 2 startup. Lots of A/V issues. CASDA support was on top of things but not so much for Airmeet support. They weren't very helpful and seemed to be argumentative at one point.
- I did! I will say that I felt some of the speakers that only had 5 minutes I wished were given more time - I felt that they got me hooked then their time was up.
- Yes and more. The palpable engagement of attendees was great.
- Yes, although there was limited interaction after the Ignite Employment Talk due to the Kahoot game starting immediately after that session. This was unfortunate.
- There was not a lot of new content, which reassures one that they are still current in the field. The format was more versatile than I had anticipated it would be; next time we could find a way to facilitate for people to network at the tables more often. I noted that at any one time there were only about 150 people on line, which means if 300 were registered, there were a lot that did not attend, or the 150 people on line were kept changing. if we have to use the ZOOM approach next time, there might be ways to keep more people engaged continuously.
- No - technical issues and sometimes going for a complex platform also causes greater opportunities for glitches and people to disconnect
- Sort of. I couldn't get into the poster talks I wanted to see (on both days), that was disappointing. I had limited networking, it was hard to start and foster conversations at the tables without a "table host".
- There is still a long way to go the policies are just about up to what I would have said was the minimum of what should have been in the blueprint to begin with but there is a long way to go.
- Yes. Developed my thinking on the great work on engaging. FOstred motivation to continue work with CASDA. Made some connections that may lead to involvement in a project (and strengthened other connections).
- Yes only issue is getting a list of names and emails for further follow ups
- Yes
- Yes - I found the update from the committees working with the pillars informative

Appendix 06

Event Feedback

Did you feel that you were meaningfully included?

- Yes (x 3)
- Everyone was welcoming and open to listening to all voices at the tables. The pre-recording of the videos made it seem less genuine. As we could have listened at our own pace. I think that the online conference is very hard to pull off. Overall I was quite impressed but personally, I was much more engaged and included with the live sections
- Yes, opportunities to be involved worked well. And opportunities for educational fun were also great (e.g. Kahoot)
- I do wish that there were pre-Summit notices about the polls; however, I did feel meaningfully included due to the nice notices about them in the chat area.
- Yes. Some of the polling questions were quite complex for just a short break and we could have used more time to reflect. I think to provide more thorough answers as the questions were quite complex and important but time was limited.
- Was confused about how polls were happening
- Yes because my opinion does matter and it could make a difference.
- What polling?
- Yes. The chats kept me in the loop of how people were feeling about the sessions.
- Yes - it was timely to be able to answer a poll right as the topic was presented / finished.
- Yes as stated, the tables provided a little networking with a potential for more next time.
- I didn't participate in the polling. I didn't see it.
- No, the focus does need to change. If this is a leadership summit what leadership skills are you promoting? If this is a promotional event call it that and I will come with less expectations.
- When the table function worked it was an incredible opportunity to learn, ask questions and connect with knowledge holders across the country. People were open and kind.

Appendix 06

Event Feedback

What parts of the Summit informed you about a NAS?

- The speakers, some of the discussion that happened at smaller groups and even the Kahoot game
- I don't think I attended enough to provide an accurate response.
- Almost every part of the summit from keynote speakers, announcements from Gov reps and content all touched upon the NAS
- Break out tables, Kahoot Game, Poster Discussion, Chat Box links
- This was weaved throughout. I will note, however, that the last time I attended CASDA (2017) the messages about the national autism strategy (particularly from politicians) were almost identical. * While I know some progress has been made, this made it feel like it hasn't moved since.
- Every single part of the Summit
- Opening remarks and IGNITE sessions.
- The keynotes, presentations and some of the Ignite talks
- Briefs were particularly informative
- n/a
- The game highlighted information in a fun way that was engaging.
- I was sent information about other organizations that don't want the Strategy and why
- All of the parts are very informative and needed as part of the national autism strategy.
- There was a thread throughout.
- The discussions and panels.
- Every part was connected but the policy papers were a good way to see how casda is working on the NAS.
- The policy briefs presentation.
- I know quite a bit about the NAS as I am on the board However the explanation of the NAS strategy was 'weaved through' very well during the 2 days. All the speakers referred to the NAS, as did the * introduction speakers, the reflection speakers and many of the presentations.
- I learned about different pieces throughout.
- Some of the policy briefs. Needed way more time on each could have easily been a whole day.
- I think I was already informed. But developed ideas about the difficult engagement work and its importance.
- The policy working groups especially.
- The update from the committees

Appendix 06

Event Feedback

What helped you in your advocacy related to a NAS?

- I feel being able to communicate directly and having access to people I would not otherwise have access with I could talk about what was important to my son and our family and how we could be a part of the solution. I don't feel I would've otherwise had an opportunity to have a face-to-face or direct communication with the same people.
- Not applicable, see above comments

same as before

still rather unsure of the role we can all play in the NAS

- Every part of the Summit
- The networking and the equity panel.
- The Ignite talks on Employment and Housing

briefs

hearing from the advocates

- I learned that I don't just talk the talk but I walk the walk
- AWNNE's video helped me. In my advocacy related to NAS.
- Last panel discussion.
- The entire thing!
- The final panel!
- Lots, but particularly hearing from the elected officials so I could hear what they are thinking about a national autism strategy.
- most of the presentations. I guess the equity panel at the end referred to advocacy related to NAS in all of their comments.
- Dr. Zwaigenbaum's information in the Keynote
- none. I still ave to go back to organization and the people we support and say there has been little in the was of progress with the exception that the government is committed to creating one (if it will get done is another topic)
- Interaction at tables, particularly where I happened to be the host and could turn it into a distributed discussion (rather than a turn-taking arrangement).
- New connections made.

Appendix 06

Event Feedback

What was the most valuable/beneficial aspect of the Summit?

- The networking being able to have access to so many people that are relevant to our lives and have an impact on how we live.
- The 2 posters that I could get a seat at where the speaker actually presented and one of the presentations
- Unable to answer.
- Networking
- Live Table discussions
- The multiple ignite sessions that allowed you to learn a little bit about a topic for many topics
- The emphasis on equity and unflinchingly mentioning human rights related issues that must be addressed for an NAS to work for as many peoples as possible.
- Networking and lounge tables

Information

- I found the Summit in whole to be beneficial-- speakers as well as the opportunity to connect with new people
 - The fact that it was nationwide
 - Connecting with others but learning what is happening around the world
 - The Tables of open discussion
 - All of it I think is very important and beneficial for others to connect and relate.
 - Networking, day 2 keynote, final panel
 - The panels - such interesting topics, and delivered by the experts. Having Autistic people who presented was amazing. Loved the game on phones.
 - The panel presentations.
 - The presentations and posters
 - Presentations/ Ignite - very helpful
 - Key notes
 - Connecting with others. Learning about research and programs across the country
 - Some of the policy briefs
 - Expanding and strengthening the network to continue and strengthen valuable work.
- the poster sessions and getting a chance to ask questions in a smaller forum
- Table conversations.
 - All the presentations/speakers

Appendix 06

Event Feedback

What was the least valuable/beneficial aspect of the Summit?

- I found the chatter about language/technology issues on the chat feature to distract from presentations. I appreciate the importance of language. E.g. deficits vs. differences. However, my son does have deficits. You can't tell me that regressing to peeing his pants is not a deficit or that he is 16 in chronological age but still cognitively like a pre-schooler.
- Posters
- The technology frustrations lead to a large meltdown. I was unable to access the second day for the better part of the morning. I wish I had prepared with the online portal well in advance rather than the weekend before the event. Could be just me.
- I love the poster format from this year (once it worked better, on day 2), but some of the posters that didn't work out (e.g. the presenter wasn't there or didn't know they were chosen) was unfortunate. I also felt that the information about the summit should have been circulated earlier than 5pm on the * Friday prior.
- There wasn't a least valuable/beneficial aspect of the Summit to me.
- Some of the technical issues ate into time for other activities like the poster sessions.
- I think there was something for everyone
- n/a
- Nothing in my view point. IN case there is no room for other comments - more time was needed for the poster tables and maybe a clearer way to indicate change of tables
- The platform was very buggy
- I can't think of one.
- The networking time - this could've been because issues with technology, but I found I wished we had more time hearing speakers or sitting at poster tables rather than the networking time.
- The games (x 4)
- The keynote speakers were OK but their content was not new to me.
- Poster presentations (bad format / implementation) cannot judge the quality of the presentations
- AirMeet—at least its many glitches and usability problems. It's a weak platform. Tables is a great feature supporting interaction, comparable to breakout rooms in zoom, which other platforms probably have. Profile photos should almost be required.
- The technical issues!
- Government presentations

Appendix 06

General NAS Poll

We asked attendees the following questions, here's what they had to say.

What are the basic standards of therapy, services and supports that autistic Canadians and their families should expect to receive, regardless of where they live?

- A variety of evidence-based ones that are also affordable
- Evidence informed, access to knowledgeable and trained professionals, across the life course, supports for caregivers as well as autistic individuals. It's not one or the other.
- Remove the word therapy, keep the word services and supports. Autism is primarily neurological., so supports like, OT, SLP, mental health are just as important as Autistic-centered behavioural supports.
- Get away from the ancient ABA / IBI early intervention. Move to PLAY based or the myriad of other therapies that give the autistic adult the skills to to be independent
- Abolishment of ABA - it is abusive Internet access (This is an oddly worded question - would it mean that a Canadian living in Toronto is viewed the same as a Canadian living in Lagos?)
- Autistic Canadians should be entitled to the amount of support needed to achieve the standard of living and of experience of a non-autistic person.
- Entitlement to services post-secondary!
- Early intervention!
- Dx, assessment, individualized plan for services and supports, early planning for transition to adulthood
- All families need to be able to access evidence-based therapy that best fits the needs of their family -- or a combination of any therapies. Whether it be ABA, PRT, Denver Model, etc. And we need to figure out how to offer these services virtually that will still be effective to reach families regardless of where they live. If you are a family living remotely, there still needs to be support to better the lives of that family. We need to also continue to build capacity across the country to deliver these much needed therapies.
- Quick access to therapy, and support for family networks.

Appendix 06

General NAS Poll

What is the most important challenge facing the development of a National Autism Strategy?

- Cohesion and a news base on the latest multi-disciplinary efforts regarding autism.
 - A united voice
 - Getting provinces and territories to have a system to talk, share, collaborate and plan standards that are centred on the Autistic individuals and their need for supports that improve their quality of life and allow them to thrive. Which means including Autistics in the discussion too.
 - Including Autistic Adult input.
 - The desire to engage in meaningful consultation with stakeholders and the challenges in identifying how to do so effectively that is inclusive and based on shared interests.
 - The voices of Autistic people being ignored or downplayed - nothing for us without us.
 - Partisanship in politics and division in the ASD community
 - Including a broad range of self-advocates in its development.
 - Funding to support this!
 - Action during a pandemic.
 - Getting PHAC to openly engage with the autism community. It all seems so secretive.
 - Collaboration across all levels of government and starting somewhere. There has been continued promise from the federal level that a national autism strategy is important, but there is still no progress towards this goal.
 - Reconciling between all the different policies across the provinces and territories.
 - Ensuring that people understand how inclusive a process the development of a NAS is, and has to be.
 - So many in the self-advocacy community have felt that their voices are not included, and nothing could be further from the truth. We have wonderful autistic Canadians on the Board as well as giving their input into the Strategy, and welcome more.
 - If autism community can not work together, governments can ignore calls to action.
- in fighting and distrust back room deals effective involvement of autistics

Appendix 06

General NAS Poll

What is the biggest opportunity or new/emerging area, method, or issue that needs CASDA investment and attention?

- The role of parents/caregivers who might have to accompany self-advocates in various stages of the job process should be looked into.
- To address the areas of controversy head on (e.g. - certain perspectives of various autism groups), but with care, clarity of position and evidence combined. Politicians will avoid signing on to a plan if they feel their alignment with this strategy will be politically challenging for them.
- Spend time to find out the needs of Autistic teens and adults. This is a massively underfunded and under researched area.
- Adult supports (independent living, employment, health including mental health)
- Engagement of lived experience.
- Intersectionality - creating safe, productive spaces for other minority groups (race, gender, sexuality, disability, etc.)
- Autistic representation at all levels
- Participatory autism research.
- Collaborations with university, service providers and advocates!
- Engaging with Indigenous leadership to ensure we remain available as a resource if needed.
- Figuring out the best way to collect histories and stories from parents/caregivers/individuals with autism.
- We can learn about the needs of autistic Canadians, their families and our larger community through the use of data mining of various datasets to inform us on the needs of Canadians.
- Income. Employment and social assistance. Independence without income is not possible.
- Strengthen relationship with government.

Appendix 06

IGNITE Talk Reflections

How can we coordinate efforts across different contexts and provinces to capitalize on each other's strengths?

- Advocate for federal healthcare and related social services to reduce inequities amongst provinces & territories. Prioritize leadership by Actual Autistics - collective, not just a few individuals who are not connected to their community nor well versed in acceptance. This should be led by Autistic self-advocacy organizations across the country with administrative and financial support from organizations with the means to do so. Inefficiencies are reduced and chance of harm reduced when the people actually impacted by the decisions get to lay the foundation for the decisions and be an integral part of the process with at least 50% decision making power by Actual Autistics. The current system is broken. We know how to fix it. Stop "consulting" and co-opting our language and hand over the reigns. Thank you.
- We need to develop Interest Groups among the community and provide them spaces to collaborate." Service discussions are likely to happen on their own and when they start a great group discussion area for that topic. then provide the information for them to move that discussion there as it is off topic for the other area. The reason for this is you get people from other interest groups talking about the service too.
- Prioritize autistic voices. Listen to us, implement what we are asking for, and compensate us.
- It would be helpful to have a list of organizations and champions listed on the CASDA website, with a brief summary of who they are, what their strengths are, and where they are looking to collaborate or coordinate efforts. I know this type of thing is difficult to keep up to date, but an annual update could be built into membership renewal and into leadership summit registration for non-members. It could have a newsfeed feature too.
- More events like this - this is an excellent national connection.
- Have Autistic people review and edit the presentations first.
- Share information and knowledge.

Appendix 06

IGNITE Talk Reflections

- Again, working together! Limited capacity is what often keeps us apart, and sometimes that means limited funds. That is an issue which at its core can stem from needing a brand new project every time to be funded instead of recognizing the value of continuing initiatives that work, and building on those. So in part, overhauling funding systems to allow for collaboration would help us to capitalize on each other's strengths." From a solutions perspective, Spectrum idea jam on that from is the Spectrum Creative Network which is meant to be an environment in which collaborations can develop - in part from a creative angle, but also with the hope that the expressive tools all would learn to use could be an avenue to build tools that share strengths. There are maybe other structures that can achieve this too, this is one idea in the employment, transition to adulthood realm that focuses on building community as a core unifying goal.
- There needs to be a more detailed and lower level discussion of autism, policies, supports and research involving the provinces and territories and an ongoing mechanism for fostering change, similar to the Finance Minister Summits and Health Summits, that can bring together health, education and social services ministries across Ontario to talk about what works, what doesn't and what the needs are for supports, research and funding.
- If you build it, they will come... I might be overly optimistic, but as a national autism strategy unfolds, I think that much of this will happen organically..." at least that's been my experience working on federal/provincial/territorial policy development roundtables in the past (although not ASD-related).
- Prioritize Autistic people. Facilitate spaces where they feel comfortable speaking up, listen to them, and compensate them.
- Find out what the barriers are to working together. Know who the champions are.
- Foster network formation and collaborative tools for the networks to leverage to stay connected and to share information (data) and knowledge (evaluation).

How can we foster (and fund) inter-provincial collaborations among researchers and policymakers to share knowledge and generate much-needed comparative information about different approaches to Autism Spectrum Disorder services and their effectiveness?

- On the foster front, I can suggest that growing national networks surrounding activities autistics enjoy could be an avenue in a variety of sectors. My bias is towards creative endeavors, and shifting, or rather adding the steering metrics of motivations that emerge from offering various supports or services. Of course this metrics suggestion could be applied to various initiatives, and would hopefully be a tool that engages autistic individuals in the steering and leadership of approaches.
- Ensure that Actual Autistics have a central role in this. Prioritize funding towards participatory research and research by neurodiverse researchers. Listen to Actual Autistics. ABA is abuse. It is conversion therapy and has no place in legislation. This Autistic vehemently opposes the National Autism Strategy. It is funded by what many consider to be a hate organization (Autism Speaks). We need neurodiversity-as-positive practice. We need "effectiveness" to also consider our mental health (see ABA and PTSD; masking and depression) not merely how "normal" we can force ourselves to look for your comfort.
- Ensure there is engagement with Allstate holders including professionals, researchers, organizations, parents and Autistics. There should be a federally managed fund similar to regional development funds.
- Maybe having a database where all of that information can be stored and accessed can be a good starting point.

Appendix 06

IGNITE Talk Networks

- I think a national clearinghouse on ASD research with some great knowledge brokers is key to proactively getting the most pertinent evidenced-based info out (in a uniform, consistent and digestible way) to key policymakers. The exchange of knowledge seems to be very piecemeal at the moment, which encourages policymakers (and elected officials) to be selective in what "evidence" or "best" practices they choose to consider / follow (and risks further entrenching whatever confirmation biases they have).
- I have no idea how to even start with this question. It is too complicated for a two-minute survey and really makes me feel like my voice as an Autistic person is valued less than the perspective of a researcher. I'm not even included in the question!
- Develop a list of policy people from each province who are interested in this project, and invite them to meetings to work on this in the first place (ie, sharing). Are policy makers (bureaucrats) interested in this? How can meetings be designed to overcome barriers to their attending?
- This would be a great funding opportunity for PHAC under a National Autism Strategy. It would help to generate evidence on what services and supports lead to the best outcomes and where the best return on investment is for governments and other funders.
- More virtual connections and opportunities to collaborate.
- Connecting with organizations (for-profit and social enterprises) to link with research and non profit community resources to identify and fill gaps in services for families. Recreational Respite provides individualized programming (1:1, groups and virtual) to reduce barriers to participation. We document outcomes of short and long term goals.
- Provide a clear set of goals for said comparative information. There are many ways to do this research, but it would be best to have some guidance as to what you are looking for and how you would like the effectiveness measured.
- This could be part of the NAS, including funding for collaboration. Now that we are more familiar with online platforms, this collaboration could be more cost effective. It would be critical to include autistic people as part of the collaborations to ensure policy and research are relevant to autistic people.

Appendix 06

IGNITE Talk Employment

What immediate opportunities exist to expand the scope of employment data & information collected across Canada?

- As I mentioned earlier, the work Worktopia is doing is a great start.
- I hope that Worktopia continues to do what it's doing. That would be a good start.
- Autism Ontario is involved in a new project that we're looking forward to launching soon.
- Connect with organizations such as auticon Canada that are working on improving employment.
- For Autistic Canadians to lead an information collection and dissemination strategy and for organizations that provide autism and employment services, supports and programs to collect common data that can be aggregated to increase the evidence to inform action.

What would you say are some gaps in federal and provincial employment programs for autistic Canadians?

- As I said, it might be the case that parents/caregivers who accompany self-advocates when needed get lost in the discussion regarding autism and employment.
- Rural areas
- One potential gap is that while there is emphasis on the issue of employment involving managers and employees, parents or caregivers who might have to accompany a self-advocate because they are non-verbal or for any reason may not be able to do the "norm" in interviews get lost in the shuffle. This needs to be looked further into.
- A central place for autistic adults and families to access employment resources by province, locally and nationally
- Follow up. You go through the program if the job placement was not the right fit, they stop helping you. An issue for All programs currently offered in Calgary.
- Lack of support in the form of OT, job coaching, counselling, etc.
- Sustained supports throughout the employment lifecycle. For example, coaching, mentorship and related supports for both the employer and employee to support job retention and career progression, not just at the point of selection and onboarding.

Appendix 06

Addressing Disparities

Autistic organizations are underrepresented in CASDA's list of partners. What are some ways CASDA and autistic organizations can work together to ensure that autistic people are involved in conversations on a national autism strategy?

- Autistic people tend to see Autism Speaks as a hate group. Autism Speaks Canada isn't materially different - there's still a dangerous focus on disorder and cure. Stop working with them.
- How do you define "Autistic Organizations?" Is the goal more organizations or more representation? Or both?
- Making connections to indigenous communities. Increasing diversity, equity and inclusion to hear and have conversations for cultural awareness and opening up discussions on how we can do better.
- Put autistic voices first. Seek out minorities and facilitate their inclusion - women, race, sex/gender, etc.
- Develop a database/file of 1) WHERE to go to meet these subgroups (eg, there may be Black Autistic Facebook group), 2) a knowledgebase of HOW to approach and connect with them (eg, is there literature on how to engage non-verbal Autistics? 3) and perhaps a roster of WHO from different groups is willing to serve on engagement committees. Think about compensation!

What are some promising practices with engaging diverse communities (e.g. Indigenous)? How can we do better?

- The leadership work of Nishnawbe Aski Nation (NAN) is in partnership with community groups, including Autism Ontario, Holland Bloorview, etc), on a Special Needs Strategy in northern Ontario indigenous communities. They are developing a wonderful autism tool kit specific to these communities. It would be good to take stock of where good work like this is happening and impacts across Turtle Island
- Put indigenous autistic people on boards and in positions of power.
- Develop a database/file of 1) WHERE to go to meet these subgroups (eg, there may be Black Autistic Facebook group), 2) a knowledgebase of HOW to approach and connect with them (eg, is there literature on how to engage non-verbal Autistics?; Indigenous engagement has lots of guidelines) 3) and perhaps a roster of WHO from different groups is willing to serve on engagement committees. Think about compensation!